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Solving the Medical Record Interoperability Issue in Low-Resource Contexts: Potential Blockchain Applications

Abstract

Blockchain has been promoted a potential solution for common issues with medical records, such as interoperability, data integrity, and lack of patient autonomy over said records – the latter of which allows for the creation of markets for data in which individuals can participate. This paper discusses whether blockchain technologies would be suitable for medical records in low-resource contexts, suggesting that it may not be the best solution to the problems faced in such contexts.

Introduction

Medical data is an unquestionably important asset in healthcare settings. A visit to a local doctor consists, primarily, of data-mining exercises. A doctor will ask you about your concerns, followed by asking about one's patient history and additional physical measurements (for example, weight and blood pressure), then followed by physical examinations in order to gain further information about physical ailments. Given sufficient time, a doctor can gain a complex, nuanced insight into your personal condition. But time is a scarce resource.

Even in the United Kingdom, a country with an advanced (though stressed) healthcare system, consultation times with General Practitioners average 9.2 minutes (Irving et al, 2017). National Health Service (NHS) standard consultation appointment durations are only 10 minutes, and have been called "unfit for purpose" especially if a doctor is dealing with individuals with multiple health conditions (RCGP, 2019). This issue is only exacerbated in lower-resource settings, where average consultation times can be as low as 2-3 minutes in countries such as India, Indonesia and Tanzania. Indeed, Irving et al. (2017) demonstrate a positive association between per capita health spending and consultation lengths.

Medical record keeping, therefore, is an important efficiency to have in a healthcare system. Medical records allow for a more efficient transfer of information from the patient to the doctor and may reduce the number of examinations that need to be performed, as well as providing a doctor greater insights in order to make a diagnosis or advise on further treatment and care.

The population level application of medical records is also important. Epidemiological applications of medical records can be traced as far back as the 1854 Broad Street Pump cholera outbreak, where case data from those afflicted with cholera, linked to their home location (and importantly, their chosen water source), allowed researchers to identify the source of the outbreak (Tulchinsky, 2018). Contemporary public health applications are obvious, where (at time of writing) targeted interventions to combat COVID-19 use case data, and their recent contacts, to isolate exposed individuals.

However, maintaining accurate, interoperable and secure medical records remains an issue. A study of a US hospital suggests that both paper and electronic records are susceptible to inaccurate inputs and omissions (Yadav et al, 2017). Much of the world still uses paper record keeping (WHO, 2012), which limits data interoperability - the sharing of patient information between healthcare providers.

However, even when electronic systems are in place, they may be bespoke to a particular healthcare centre, allowing for greater internal sharing of data but lacking the ability to share this information with other healthcare centres. Additionally, current electronic systems remain susceptible to security threats, as noted by the WannaCry NHS data breaches (Parliament Street, 2018).

All of these issues are only exacerbated in low-resource contexts where the healthcare systems have lower capacity to implement well-performing record-keeping within healthcare centres, with many published anecdotal reports of inaccurate data-entry and files being lost while performing clinical trials and research in lower-income countries (Dainton and Chu, 2017).

Blockchain has been proposed as a potential solution to the accuracy, interoperability and security issues associated with electronic health records. Claims have been made that blockchains – cryptographically linked blocks of records - allow for the accurate and secure storage of medical records, while maintaining access to such records for healthcare stakeholders, and providing individual autonomy over their personal data.

This paper will discuss the current state of medical record keeping in examples of a high- and low-resource setting, the UK and Tanzania, current block-chain technologies being used to facilitate decentralised record keeping, and a critical discussion of whether such technologies could be applied in low-resource contexts to improve medical record keeping and, in turn, improve patient care. The UK and Tanzania have been chosen as contrasting case-studies for this paper, as their differences in healthcare system resources and structures, as well as the experience of this paper's author in both of these systems, provides the grounds for the discussion of blockchain solutions to medical record interoperability.

Medical Record Keeping in Low-Resource Contexts

In order to provide a grounding for discussions of the potential of blockchain applications for medical records in low-resource settings, this section will provide an overview of common trends in medical record keeping in the UK and Tanzania as examples of settings with contrasting resource levels.

A number of models have been adopted by the World Health Organisation (WHO) in order to assess the level of information technology (IT) adoption in the health sector, and provide useful benchmarks for comparing the development of IT systems. (WHO, 2012). The first model is the

Capability Maturing Model (CMM) which defines give maturity levels of process adoption, which are described in Table 1. When applied to medical record systems, level 1 capabilities would describe a clinic without any processes for storing medical records outside the efforts of individual doctors and nurses to make notes.

Table 1 - Capability Maturity Model (Source; WHO, 2012)

Levels	Label	Description
1	Initial	Chaotic, ad hoc, individual heroics – starting point for use of a new process
2	Repeatable	Process is able to be used repeatedly, with roughly repeatable outcomes
3	Defined	Process is defined/confirmed as a standard business process
4	Managed	Process is managed according to the metrics described in level 3 (data collection and analysis)
5	Optimised	Process management includes deliberate process optimisation

Low levels of medical record system capabilities is more common in low-resource settings due to multiple barriers to process adoption. From a supply-side lens, the workload of doctors and nurses is high, and consultation times low, such that having the time to review available medical records or accurately record patient data is low. Even in the cases where there is some defined practice of recording medical records, issues remain in storing and accessing such records if a healthcare centre is using paper records – a practice that is much more common in lower-income countries (WHO, 2012; Akhlaq, 2016). Further barriers stem from demand side issues, such as differing attitudes to the importance of medical records. For example, research from India, Kenya, South Africa and Tanzania found healthcare stakeholders gave low importance to data, and therefore did not use available health information when making clinical decisions (Akhlaq, 2016).

The capability of healthcare systems to adopt electronic healthcare records as a standard is limited by further structural barriers. Healthcare centres are less likely to have the recourses available to invest in IT systems, as adopting such systems are not only expensive in upfront monetary costs, but also burdensome and resource intensive in retraining staff in using such systems and in organising the effective coordination, management and supervision of different departments in adopting the use of a new IT system.

Interoperability of healthcare records is a further issue. Even if electronic medical record systems have been adopted in a given healthcare centre, there may be limited ability to share such medical records with other healthcare centres responsible for patient care. Table 2 shows the Interoperability Maturity Model, where level 1 describes the initial stage of medical record interoperability.

Table 2 - Interoperability Maturity Model (Source; WHO, 2012)

Levels	Label	Description
1	Initial	Early awareness of eHealth interoperability requirements and characteristics, perhaps some initial eHealth interoperability solutions adopted at local level
2	Repeatable	An organisation will begin accomplishing interoperability goals e.g. adopting specific eHealth standards, early shared understanding of data services, initial governance established
3	Defined	An organisation has defined set guidelines for adoption of eHealth standards, for data, services and processes. Communication standards established for interaction between internal and external partners
4	Managed	An organisation has established processes for appraising and measuring eHealth interoperability
5	Optimised	An organisation has implemented processes to support continuous interoperability improvements, driven by feedback from monitored processes

An anecdotal example of poor medical record interoperability can be drawn from healthcare centres in Dar es Salaam, Tanzania. The Tanzanian healthcare system has a decentralised structure and consists of public and private hospitals, where public hospitals tend to have fewer resources and greater usage by lower-income individuals, while private hospitals are able to charge higher-income patients, thus are generally better financed. While public hospitals on the whole have lower level of capabilities for medical record keeping (level 1 or 2 in the CMM model), private hospitals tend to have better defined processes of record keeping (level 3 in the CMM model). However interoperability remains low – even between private healthcare centres. Private hospitals are more likely to have bespoke electronic health record systems that promote efficient information transfer within a hospital (i.e. between various departments), but these systems are not interconnected with other healthcare centres. Therefore interoperability remains low at the patient level. While various Tanzanian government departments have been contributing to the development of a national health information system, that provides a means of collecting healthcare data in the aggregate for public health purposes, the patient-level access to health records remains low (Nsaghurwe et al, 2021).

The UK's NHS, as a stark contrast, lies around level 4-5 in medical record capability and interoperability, since most systems are digitised and allow for the exchange of data between healthcare centres, and NHS Digital – the organisation responsible for driving the NHS' digital strategy – continues to work on optimisation these processes. However, not all aspects of the NHS are digitised. Many hospitals and pharmacies (depending on the department and healthcare centre) continue to rely on paper-based records for record keeping, and the NHS continues to have a backlog of historic paper-based medical records.

Therefore, in the Tanzanian context, medical records are primarily paper-based with some digitisation at larger health centres such as national and private hospitals. Current medical record capabilities range from being chaotic to well-defined, but interoperability remains low or non-existent between different healthcare centres. This contrasts with the experience in the UK which has a higher-level of medical record interoperability, though it still has gains to be made in this area.

Blockchain Technologies and Medical Records

Conventional medical record systems, especially in low-resource contexts, struggle to make medical records accessible to patients or allow for interoperability of medical records between healthcare centres responsible for a given patient's care. In a healthcare system lacking interoperability, patients have to request their medical records from a given healthcare centre and become the medium of communication themselves. Digitising healthcare systems helps to improve this means of transmission, however it still relies on the patient to request the digital data in order to forward it to another healthcare provider. The standard approach to improving interoperability is to then set-up a health information mediator in order to allow for the sharing of digitised records from various

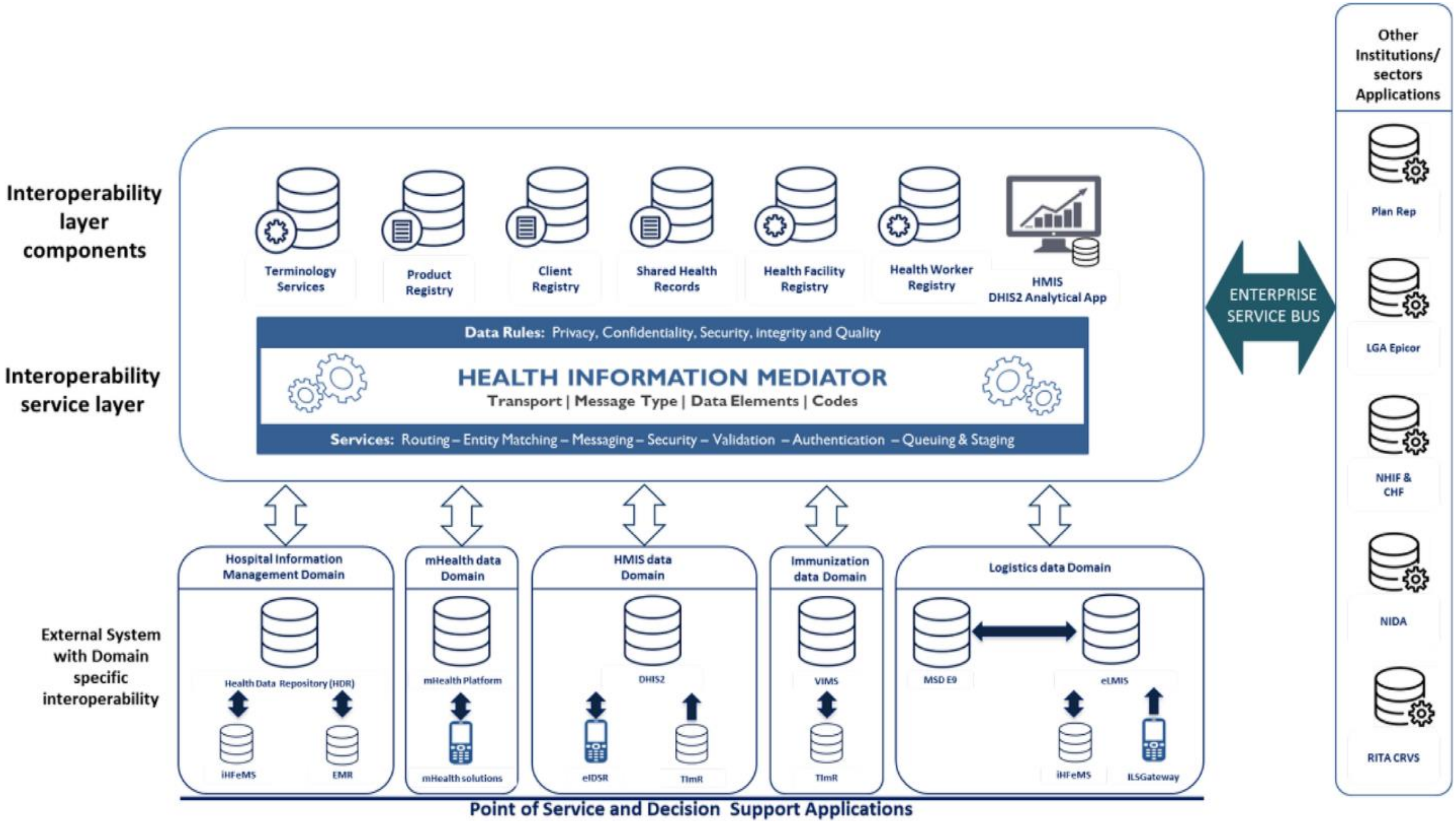

Figure 1 - Tanzania's Health Information Exchange Blueprint (Source: Nsaghurwe et al, 2021)

databases, demonstrated in Figure 1 by the blueprint of the health information exchange (HIE) currently being implemented in Tanzania.

The UK's NHS benefits from a centralised structure, such that centralised databases can be accessed by the various clinics and hospitals operated by the NHS, and data from locally based databases can be requesting via messaging services. This is not done without difficulty, however, since the vast number of different databases that require linking, some of which are legacy systems – which in turn lead to compatibility issues – leads to a complex system architecture. Hales et al (2019) capture this complexity when discussing the University Hospital Southampton digital infrastructure which links information not only from the various hospital departments and hospital management, but also links with the wider network of local GP practices. The centralised structure leads to bottle-necks when patient data flows through the system (Uddin et al, 2021).

When setting up a new health information mediator or health information system, this is perhaps the one area where lower-income countries have a potential advantage, since they do not have to deal with such legacy issues, providing greater flexibility in the implementation of a new system. However, in contexts where healthcare providers are not centralised and there exist legacy issues due to differing implementation of record systems, implementing interoperable medical records becomes more difficult.

Authors studying the applications of blockchain to medical records suggest that blockchain provides a secure means for solving interoperability issues as well as maintaining patient control over their medical data (Zhang et al, 2017). A blockchain is a distributed ledger with an immutable record of transactions (Carter et al, 2019), and can ensure that the majority of network nodes (other users in the network) validate the information to be stored on the ledger before it can be posted to the ledger, based on stated and agreed rules (Uddin et al, 2021).

Blockchain, therefore, has the advantage of ensuring that the stored blocks of information (i.e. medical records in this application) are immutable, reliable, secure, and trusted due to the verification and validation of data on the network by a majority of nodes on the network, so there does not exist a single point of failure as found in conventional systems (Uddin et al, 2021).

Uddin et al. (2021) suggest Blockchain-enabled efficient electronic medical records systems comprise of the following workflow in seven steps, laid out in Table 3 and Figure 2, which has been modified to be include other possible interactions in low-resource settings.

Table 3 - Workflow of medical records in Blockchain-enabled efficient medical records system

Step	Description
1	Patient visits a physician/is visited by a healthcare worker. Patient data consists of medical history, current medical issues and other physiological information. Data is stored on local database (e.g. in hospital, or submitted via an online/app form to local database)
2	Medical record is generated from the step (1) data, and attached to other medical information (e.g. laboratory results, imaging and drug-history)
3	Owner of medical records has the sole authority to give different access rights and permissions of sharing in order to achieve data privacy and secrecy across the healthcare sector
4-6	Medical records are now permanently stored in the blockchain ledger and decentralised storage systems, while the local database ensures that patient records can be modified and stored locally before updating the ledge
7	Healthcare centres who have authorised access to the blockchain ledger have access to the ledger, enabling the secure and transparent transfer of medical records, solving interoperability issues.

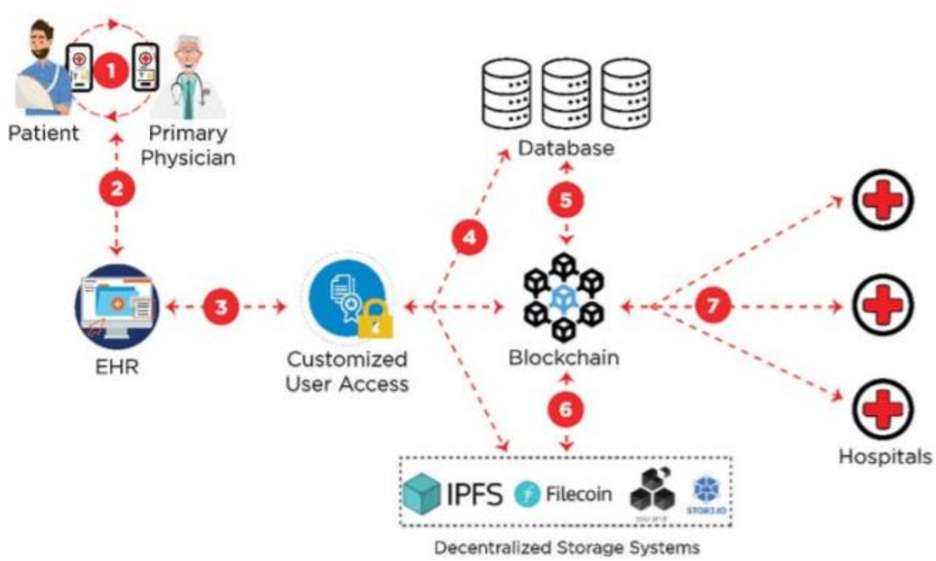

Figure 2 - Blockchain-enabled medical records management in healthcare (Source: Uddin et al, 2021)

Many blockchain implementations of medical record management systems have lacked the desired characteristics of such a system, namely being secure, solving interoperability issues, allowing patient access, maintaining privacy of patient data, being practical in terms of storage capacity, and ensuring sufficient regulation of access and authorization to use the blockchain ledger (Uddin et al, 2021).

However Hyperledger Fabric, a distributed ledger platform with a modular architecture, has been proposed (and implemented) as a Blockchain tool for healthcare data management. Hyperledger Fabric has a number of desirable properties, such as the creation of private permissioned blockchains where different healthcare stakeholders and end-users are identified, registered, and connected using different channels, controlled by a regulator, to provide maximum privacy, confidentiality, data secrecy and scalability. It also can execute more than 3,500 transactions per second (Uddin et al, 2021).

Such an architecture means that healthcare providers, patients, insurers, researchers etc. are able to access electronic medical records from decentralized storage systems, provided they are authorized to access the data. The authorization is regulated by a health authority, who can register the various healthcare stakeholders to access the ledger, and by the patient who can control access and sharing of their data between any other healthcare actor.

A current implementation of Hyperledger Fabric as the architecture behind a medical record system is provided by MedicalChain (MedicalChain, 2018). Based in the UK, it is working with NHS trusts and departments to design future medical records systems, while also providing health service software for remote consultations (GOV UK, 2021).

Therefore blockchain provide a promising and practically implementable solution to creating ideal medical record systems, which are already seeing real world implementation.

Is Blockchain a Solution for Medical Record Keeping in Low-Resource Contexts

Blockchain technologies have the ability to create a medical records system that is capable of solving interoperability issues while also providing patient autonomy over data, without compromising security or performance. However, this section will discuss its practicality of implementation in low-resource contexts, taking the Tanzanian context as a key example.

Recalling the capabilities of healthcare centres and as an extension, healthcare workers, in collecting, storing, and sharing medical records; centres lacking capacity to implement repeatable medical record-keeping are likely out of reach of blockchain technologies. Ultimately the success of such a system, at its base level, relies on the reliable inputting of data onto the ledger. Given many healthcare centres are still working with paper records, if any, the transition to a blockchain based medical records system requires a baseline digitisation. This applies to both any blockchain system that is introduced, or linking healthcare centres to traditional centralised data servers and mediators.

That said, a blockchain system could remove the usual barriers to digitisation. In the standard digitisation case, as can be found in hospitals around Dar es Salaam, bespoke medical records systems are implemented in each healthcare centre, with computer terminals installed around each department linked to a local network and database. The upfront cost of the technologies, and ongoing maintenance of such technologies at the local level, is expensive. In addition, it is susceptible to failures if a blackout occurs in the city, which is not an uncommon occurrence. However, smartphones have a high penetration in country – with 43% of Tanzania now having internet access, primarily through smartphones (ITWeb, 2019). Therefore a mobile application service could link patients and healthcare professionals with the distributed ledger in a secure manner. A similar Hyperledger Fabric architecture described in the previous section has been applied to mobile applications by Liang et al (2017). This would reduce the demands on local healthcare centres with few resources for digitisation, but where smartphone access is high. While rural clinics may not immediately benefit from a blockchain based medical record system until greater internet connectivity and smartphone penetration is achieved, patients and healthcare centres in connected but low-income areas could benefit.

The fact that there exists many non-digitised healthcare centres in Tanzania using paper-based systems also means that the potential gain from implementing a blockchain medical records system is greater than the potential benefit seen in the UK. The UK's NHS struggles with legacy systems and a backlog of paper medical records that, to this day, are being digitised by healthcare centres around the country. Tanzania, however, has the ability to start from scratch in many areas, and define processes suitable for the adoption of a blockchain-based medical records system.

The ultimate question for blockchain technologies being used for the construction of new medical record systems is: does it really lead to a tangible benefit, in terms of factors such as security and efficiency, over conventional databases and interactions between users and databases? So far, as demonstrated by Tanzania's Health Information Exchange design, and the lack of NHS implementation of MedicalChain beyond local pilots, apparently it is not yet considered a strong alternative.

Conclusion

Solving medical record issues in low-resource contexts, in terms of improving patient-access to their records, record keeping in centres with low-resources, and interoperability between centres with low-resources, is not something that can be solved with the pull of a single lever. The structural barriers faced in such centres goes beyond technological; the demand for improved medical record systems may be low and not valued, the technological and human capacity for adopting digitised systems may be non-existent, and political and legal difficulties in developing such systems and enforcing appropriate data standards and protections (Akhlaq et al, 2016).

Blockchain technologies have a small niche where they can operate. Technologically connected individuals and healthcare centres that are able to communicate with decentralised databases, with access controlled through blockchain architectures such as Hyperledger Fabric, provide a means of improving interoperability, security, and patient access. Given it is technically feasible, as has been considered in this paper, it is not immediately obvious whether it is also an acceptable solution in many other dimensions that pose barriers (i.e. the political, legal, cultural, and financial aspects). Therefore further research is required in low-resource contexts in order to answer these more difficult questions.

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